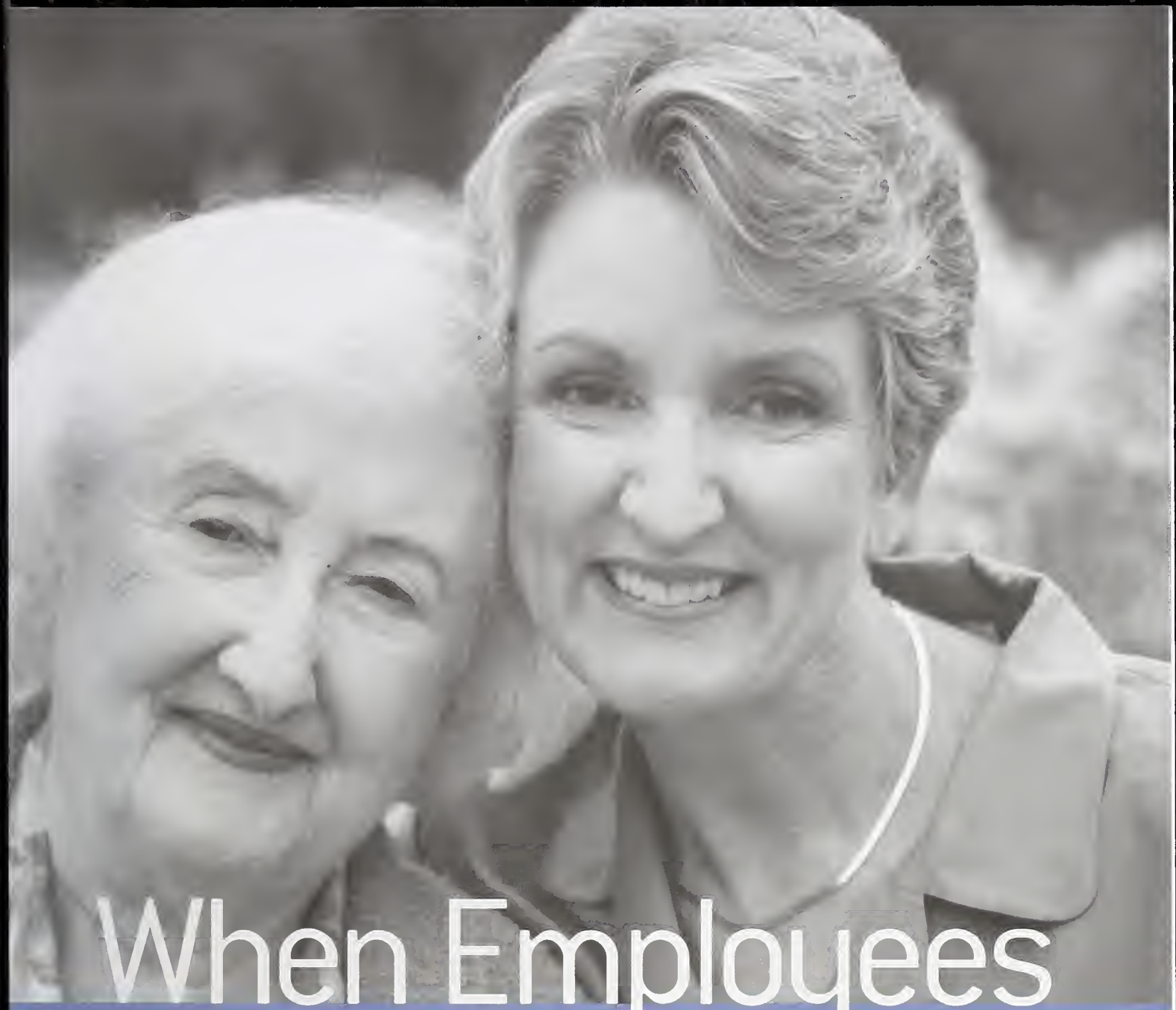

When Employees Become Caregivers

A Manager's Workbook

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DEPARTMENT OF HEALTH & HUMAN SERVICES USA

CMS
CENTERS for MEDICARE & MEDICAID SERVICES

**A new challenge for employees—
a new reality for American business.**

Eldercare

This document guides employers in how to make needed eldercare and Medicare information available to caregiving employees at little or no cost.

Although this publication is directed to caregiver issues for the elderly, similar needs and issues are present regarding younger people with disabilities. This publication may also be helpful in identifying services for these individuals.

The Centers for Medicare & Medicaid Services want to thank the National Alliance for Caregiving and its President, Gail Gibson Hunt, for their cooperation and effort in developing this document.

In the 1980s, American businesses adapted their human resource policies to accommodate the needs of workers with young children.

Now, many of those same workers face a new responsibility: providing care for an older parent, relative or friend.

Important: The information in this handbook was correct when it was printed. Changes may occur after printing. For the most up-to-date version, look at **www.medicare.gov** on the Internet. Select "Publications." Or call 1-800-MEDICARE (1-800-633-4227). A Customer Service Representative can tell you if you have the most up-to-date version. TTY users should call 1-877-486-2048.

"When Employees Become Caregivers" explains the Medicare program. It is not a legal document. The official Medicare program provisions are contained in the relevant laws, regulations, and rulings.

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1 A Challenge to American Business

Eldercare: An opportunity for adaptable companies.

Just as childcare did, the growing need for eldercare presents companies with a new reality—workers who must juggle multiple demands on their time and energy. Yet this reality presents genuine opportunities for those firms that recognize it. By implementing policies that are "eldercare friendly," companies will:

- Find it easier to attract and retain the best workers
- Increase productivity by reducing stress on employees
- Reduce disruptions in the work schedule
- Enhance their community image, which can attract new customers

Just how critical is the need for eldercare?

As we've all heard, America is growing older. According to the U.S. Census Bureau:

- Today's older population of more than 35 million Americans will increase to over 70 million by 2030[1]
- Today, 33.9 million caregivers provide help to persons age 50+[2]
- The segment of the older population most likely to need care—those over the age of 85—is the fastest growing segment of elders today[3]
- 80% of all the care received by older adults is provided by family and friends[4]

And, yes, 2030 is a long way off, but the need keeps growing with each passing day. The fact is, as more and more Americans live into their 80s and 90s, their adult children and relatives will assume increasing responsibility for helping with the daily business of living.

More working Americans are also taking care of an elder. There are currently about one out of five workers who are balancing work and caregiving. This will increase in the future due to:

- Growth of older population
- Smaller family size
- Increase in two-earner households

What is the cost to American business?

Managing the responsibilities of home and eldercare isn't easy for workers. One survey revealed how the stresses of eldercare affected employee productivity:[5]

- 56% of respondents said they were less productive at work
- 51% said they had to take time off during the work day for eldercare
- 30% reported being absent for a full day to deal with eldercare matters

And in a survey done by the National Alliance for Caregiving and AARP in 2004, 6 percent of working caregivers had to give up work entirely.[6]

1 in 5 Americans are helping an elder

1

Lost productivity costs businesses $11.4 to $29 billion annually.

A 1997 study by MetLife found eldercare issues cost businesses $11.4 to $29 billion a year.[7]

Companies lose so much each year because of costs due to the eldercare crisis:

- Replacement costs for employees who quit due to caregiving responsibilities
- Costs due to absenteeism/partial absenteeism
- Costs due to workday disruptions
- Costs associated with supervising employed caregivers

How will your business respond?

In the sections of this workbook, you will find suggestions and guidance for implementing various levels of eldercare programs. A comprehensive program might be expensive, but there are many initiatives that can be implemented with little or no cost.

Obviously, how you and your human resources department will respond to the eldercare needs of employees will be based on your organization's individual circumstances.

It is important to remember that the need for a response gets greater every day. And the cost to your business of not responding will only get larger, too.

2 Meeting Employee Eldercare Needs

The basics...at no cost.

If your company has limited resources at this time, there are several no-cost steps you can take to indicate that eldercare is now on your "radar screen."

- Guide your employees to "Medicare Basics" and other resources available at www.medicare.gov and 1-800-MEDICARE (1-800-633-4227)

Just by taking these simple steps, you can let employees know you recognize the problems they may be confronting. You'll save time by providing this valuable reference, organized to provide information at the times it's needed most.

Why is Medicare talking about eldercare?

You may have asked why the Centers for Medicare & Medicaid Services (CMS) is bringing employers information about eldercare. The fact is, as the nation's largest provider of health care coverage to older Americans, CMS knows firsthand the problems faced by those who care for or advise people with Medicare. Each year, CMS receives millions of inquiries by mail, phone, and e-mail from people who are helping older Americans make health care decisions or access their benefits under the Medicare system. CMS believes that employer eldercare programs, no matter how basic, will benefit those providing eldercare and ultimately those they help.

Internet Quick Find

www.medicare.gov
Click Publications: Check "Medicare & You" for basic information on Medicare or "Medicare Basics" for a quick reference guide. More detailed information is available on selected topics.

www.aarp.org
AARP serves the needs of people age 50 and older by providing outreach, education, advocacy and community service. Information for caregivers is available at www.aarp.org.

www.alz.org
Click Resources: Search the Resource Center to learn more about Alzheimer's disease and care strategies through downloadable publications. Also includes 100+ links to Alzheimer- and care-related websites, information on programs and services, bulletin boards, and resources in other languages.

www.aoa.gov/caregivers
Click "Elders and Caregivers—A Guide for People Who Care." This guide provides helpful information for family caregivers and others responsible for providing care.

www.caregiving.org
Click Reports and Products: See "Resources for Caregivers," a publication from the National Alliance for Caregiving with contacts for those caring for an older relative or friend.

The next level: creating your own "how to" guide for employees.

Don't worry...we're not talking about putting together a big, expensive manual. This guide can be as simple or as complex as you need. How complex it will be is determined by the extensiveness and formality of your benefits and programs.

The basic packet.

If your company is small and/or one with few or no formal benefits or policies in place, you can still help your employees. Provide employees with information and support by reaching out to community groups and caregiver organizations.

(See the list of Internet addresses on page 13 for organizations that can give information on specific topics.)

Some of the local groups you can contact for information include:

- Area Agencies on Aging (These organizations have comprehensive information about all programs in the area that serve older adults. Most groups also have special programs for caregivers.)
- Hospitals
- Senior centers
- Faith-based organizations (such as Catholic Charities, United Jewish Appeal, etc.)
- Disease-specific organizations (e.g., Alzheimer's Association)
- Local universities and community colleges or cooperative extension programs

2

Keep your packet simple.

Again, if you have a small company, your eldercare packet may be no more than a few pages created on the office computer and photocopied. You can also include information from organizations that are active in your area. Simply give a copy to each current and new employee. Corporate acceptance of worklife issues is important to employee acceptance of them.

Perhaps adopt a few simple policies.

If your company is small enough, you don't even have to adopt written policies. On an informal basis, you can try:

- **Flex-time, shortened work weeks, modified daily schedule based on need**
- **Telecommuting**

Allowing your employees to help one another through such flexible policies will also help build company morale while keeping productivity levels where they should be.

Flexible eldercare policies can also help build company morale.

Internet Quick Find

www.medicare.gov

Click Publications: Search "Medicare Preventive Services" for a listing of benefits covered by Medicare. More detailed information is available on selected topics.

www.aarp.org

AARP serves the needs of people age 50 and older by providing outreach, education, advocacy and community service. Information for caregivers is available at www.aarp.org.

www.shrm.org

Search caregiving or eldercare for a range of resources for human resource professionals from the Society for Human Resource Management. SHRM is the world's largest association devoted to human resource management and represents more than 170,000 individual members.

www.sba.gov

Visit the website of the U.S. Small Business Administration for information on a range of business issues. SBA provides financial, technical, and management assistance to help Americans start, run, and grow their businesses.

Comprehensive benefits approaches for larger companies.

Owners or managers of larger companies may want to fold eldercare policies into their overall existing benefits and policies package. This means that creating your eldercare information packet should begin with an examination of benefits to see which apply to eldercare already or might be refined to provide an eldercare benefit. The National Alliance for Caregiving suggests that the benefits and policies be included in your eldercare information package. Supportive benefits are listed below.

Supportive Benefits.

- Dependent life insurance
- Long-term care insurance covering spouse and parents/ parents-in-law
- Flexible spending accounts/ dependent care accounts
- Cash subsidies for services for older relatives
- Group legal/financial plans
- Travel discounts (can help with long-distance caregiving)
- Hospice inclusion in company-sponsored health insurance
- Access to Employee Assistance Programs (EAPs) for counseling and support

2

Your employees will value and appreciate comprehensive information on eldercare resources.

Supportive Policies.

- Paid sick leave that can be used to care for relatives or friends who are ill
- Paid family leave that can be used to care for ill relatives or friends
- Leave without pay options
- Flex-time
- Compressed work schedules that allow an employee to work more hours during the work day and fewer days in the week
- Flex-place policies that allow telecommuting
- Temporary reduction of hours
- Job-sharing
- Employee leave-sharing, where employees donate a portion of their leave time to others who have eldercare responsibilities
- Shift-exchanging, allowing employees to swap shifts on an as-needed basis, especially when emergencies arise
- Gradual return to work policies
- Funeral and bereavement leave policies

Add community resources and you're done.

Larger companies can also make employees aware of the community resources available. See "the basic packet" on page 7. Add those organizations' phone numbers and Internet addresses to information on your own policies and benefits and you'll have a comprehensive package that your employees will value and appreciate.

Find eldercare information with one phone call or on the Internet.

Your employees may, of course, live hundreds of miles from their loved ones and be providing care "long distance."

There's a toll-free, nationwide "Eldercare Locator" number that can help: 1-800-677-1116. (Weekdays, 9:00 am to 8:00 pm e.t.) One call will let employees get contact information for Area Agencies on Aging throughout the U.S.

Or, you can look at www.eldercare.gov on the Internet for more information.

3 Seminars on Aging and Eldercare

A low cost way to educate your workforce to make good choices.

It's easy to partner with community organizations to put on seminars at your place of business. For example, you can set them up as lunch and learn sessions. Just be sure to schedule a convenient meeting time and place. Give employees plenty of advance notice.

You may need to hold multiple sessions on each topic in order to maximize attendance without disrupting your work schedule.

Here are some popular sample topics:

1. Medicare/Medicaid

Many employees have questions about Medicare and Medicaid. Contact the State Health Insurance Assistance Program and see if they can send an expert on what Medicare covers, who is eligible, how to enroll, and how Medicaid covers medical costs for those with limited resources. You can also access www.medicare.gov to get a free copy of "Your Medicare Benefits" booklet (CMS Pub. No. 10116).

2. Planning for Long-Term Care

Unfortunately, too many caregivers don't think about long-term health care needs until there is a crisis. Contact your local Area Agency on Aging to see if they can send an expert on the topic to address your employees' questions. You can also access www.medicare.gov to get a free copy of "Choosing Long-Term Care" booklet (CMS Pub. No. 02223).

3. Health Care as You Retire

Your younger workers may have parents reaching retirement age, while older workers should begin planning now for post-retirement care. Again, someone from your State Health Insurance Assistance Program may be able to answer your employees' questions on Medicare. Also, a local hospital may have someone available to speak about health care as you retire.

4. What is "Normal" Aging?

People who provide eldercare often wonder about "normal" signs of aging as their involvement with an older person progresses. A geriatrician (physician who specializes in older patients) or a geriatric social worker can teach employees when things such as mental deterioration are not "normal."

5. Alzheimer's Disease

If you live in a fairly large community, you probably have a local chapter of the Alzheimer's Association which can provide a speaker on Alzheimer's Disease. Recognizing the onset of this disease is a key to quality of life for both the elder and caregiver. For more information, call the Alzheimer's Association at 1-800-272-3900 or you can access www.alz.org.

6. Community Resources for Older People

There are many community resources available to older adults, ranging from adult day care at community centers to nutritional programs. Services are also available for caregivers. Your local Area Agency on Aging can either provide, or help you find, a speaker. For more information, access www.aoa.gov.

7. Taking Care of Yourself as a Caregiver

Caregivers are often under such stress and severe time constraints that they neglect their own physical and mental health. Local caregiver groups, such as Children of Aging Parents or an adult-day care based caregiver group, may provide speakers on this topic.

In most cases, the speakers are free.

You can contact professionals in the aging field to come and speak to employee groups.

The websites below can provide you with more information and can also serve as resources for your employees.

Planning for Long-Term Care

Medicaid
www.cms.hhs.gov/consumers

Medicare
www.medicare.gov

American Association of Homes and Services for the Aging
www.aahsa.org

American Health Care Association
www.ahca.org

AARP
www.aarp.org

Alzheimer's Disease

Alzheimer's Association
www.alz.org

Community Resources

Administration on Aging
www.aoa.gov

What is "Normal" Aging?

Administration on Aging
www.aoa.gov

Healthfinder
www.healthfinder.gov

National Institutes of Health
www.nih.gov

Health Care as You Retire

Administration on Aging
www.aoa.gov

Healthfinder
www.healthfinder.gov

National Institutes of Health
www.nih.gov

Taking Care of Yourself as a Caregiver

Careguide
www.careguide.com

National Alliance for Caregiving
www.caregiving.org

National Family Caregivers Association
www.nfcacares.org

Build an eldercare file as you go.

As you arrange your seminars, talk with community groups and exchange information with professionals. Start accumulating the brochures, fact sheets and booklets they have to offer. Begin with your local Area Agency on Aging—they should have a substantial amount of material to share with you and can direct you to other resources, such as groups that deal with specific conditions or diseases common in the elderly. Also, be sure to refer to "Medicare Basics," a resource for caregivers, available at www.medicare.gov.

By gathering information and keeping it in your personnel or employee assistance office, employees will have a quick, easy source of information that they can access in privacy.

3

Bring the Experts to You: Host A Caregiver Fair

Caregiver fairs, bringing the community and the workplace together.

Caregiver fairs are an excellent way to allow employees access to a wide range of information in one day. Agencies typically come to the fair with brochures and other information to help employees make eldercare decisions. All you have to do is provide the space and perhaps some tables.

Your Area Agency on Aging can help you get started. Also, if your business is too small to host such an event, local hospitals or senior centers may already have a similar program scheduled. Then it's just a matter of giving your employees time to attend the fair at an offsite location or you could join with other businesses in your building to host a fair in a common space.

Most employees are interested in getting information from:

- Medicare (State Health Insurance Assistance Program)
- Medicaid and state programs
- Hospice organization(s)
- Area Agency on Aging
- Disease-specific groups, such as Alzheimer's Association, Parkinson's Association, and groups with information about vision and hearing impairments
- Legal Aid and/or legal assistance organizations
- Financial professionals
- Home health programs
- Home-delivered meals programs
- Counseling programs

Training for Supervisors 4

Training Supervisors to Manage Eldercare Issues

Awareness can prevent workplace concerns.

Workers often say they have difficulty getting their supervisors to understand the concerns caregivers face balancing work and family obligations. By training supervisors to recognize and respond to eldercare issues promptly and effectively, you can keep these issues from becoming problems.

The following training program can help you do that. (This program, along with other information in this workbook, was developed by the National Alliance for Caregiving, a group that provides support to family caregivers.)

Supervisors trained to respond to eldercare issues can prevent problems.

4

Supervisory Sensitivity Training: a 60-minute program.

Training Objectives

- To increase the knowledge of line supervisors regarding the impact of caregiving in the workplace
- To develop their knowledge of what community resources are available to support employed caregivers

Audience

Line supervisors and mid-level managers in small and mid-sized companies. No more than 25 people per session.

Format

A 60-minute session, conducted by staff from employee assistance or personnel, along with an invited Area Agency on Aging representative to present information on community services for caregivers and older people.

Content

I. WHY IS ELDERCARE AN ISSUE? (10 minutes)

Demographics

- 20-25% of employees are caregivers of elderly relatives, and about 40% of these people are also caring for children under 18 living at home. (These numbers do not count parents caring for children with disabilities or for disabled adult siblings or spouses under 50.)[8]
- Gender: 55% of employed caregivers are women/45% are men. Most are married, work full-time, and have a median age of 46.[9]
- The older your workforce and the more females you employ, the higher the incidence of caregiving in your employee population.[10]

Impact on Productivity

- More than half of working caregivers have to make some sort of workplace accommodations to care for someone age 50+, such as:[11]

Went in late, left early, took time off during work	58%
Took leave of absence	16%
Worked fewer hours, took less demanding job	10%
Lost any job benefits	4%
Turned down promotion	4%
Chose early retirement	3%
Quit their jobs entirely	6%

- In one study of working caregivers who provide intense personal care over a period of years, the caregivers averaged $659,000 in lost wages, pensions, and Social Security.[12]

Impact on Worker Health

- Almost 75% of employed caregivers in another study say that caregiving has had a negative impact on their health, with more than two in ten reporting significant problems.
- Of those reporting a negative impact on health, nearly half cited additional visits to a health care provider.
- Employed caregivers' use of prescription drugs is 2-3 times that of non-caregivers.

Impact on Caregivers' Personal Life

- 35% of caregivers report significant emotional stress; 15% report that caregiving has caused physical strain.
- Caregivers report average out-of-pocket expenditures of $197 per month for medications, groceries, or other kinds of cash support.
- Half of caregivers report that they have less time for friends or other family and more than four in ten say they have given up vacations, hobbies or their own social life.

How Does This Affect Your Company?

- Total lost productivity for U.S. employers due to caregiving for older relatives: $11.4 to $29 billion per year.[13]
- You have spent considerable dollars training and promoting these working caregivers. The cost of replacing an experienced employee is estimated at 93% of the first year's salary.[14]

II. HOW DO I RECOGNIZE AN ELDERCARE PROBLEM? (10 minutes)

Possible Signs of Eldercare Work/Family Conflicts

- Excessive personal phone use during office hours.
- Tardiness and absenteeism that far exceed company standards.
- Claims for sickness benefits at a much higher than usual rate.
- Serious distraction on the job that is reducing productivity (work isn't being done properly and sometimes has to be done over by someone else).
- Mood swings and hostility that have fellow employees confused and reluctant to work with the troubled person.

While these signs may be indicative of other employee problems, supervisors should be proactive but sensitive in identifying if eldercare is an issue.

4

Supervisory Sensitivity Training: a 60-minute program ...continued

III. MINI-CASE EXERCISE (15 minutes)

Break participants into small groups. Ask each group to take 10 minutes to discuss a case and answer the following questions: What should you, as a supervisor, recommend the employee do? What are your options under the company work policy? What should you do if the employee doesn't respond? What is your obligation to other employees?

Case A: Jim has been coming into work exhausted for weeks now. His productivity is down and he is snapping at his colleagues over trivial things. When you call him into your office to ask about this, he confesses that every weekend for the past two months he has been driving 500 miles roundtrip to help his elderly father who lives alone on a farm and is becoming increasingly depressed. The father is calling him several times a day at the office as well as in the middle of the night at home. Jim feels compelled to help his dad but has no idea where to turn for help. Meanwhile he is exhausting himself.

Case B: Karen is an energetic young single mother with two small children who recently has been coming in late and leaving early. Her absenteeism is beginning to affect the office. When you confront her about her pattern of tardiness, she becomes very upset and defensive. Eventually Karen tells you that in addition to having child care problems, she has suddenly become the caregiver for a maiden aunt who has had a series of small strokes. The only relative living nearby, Karen is going to the aunt's house every morning before work to fix breakfast and dress her, then taking the kids to day care. In the evening, before going home, she rushes over to make dinner, bathe and feed her aunt, pick up her kids, and then go home to her own dinner and housekeeping. Karen is frustrated by having no money to pay for caregiving help, and is feeling

overwhelmed because she is the only one around to help.

Case C: One of your most valued employees, Lucia, comes to you unexpectedly to say that she is thinking about dropping back to part-time or maybe quitting entirely. Her husband was diagnosed with MS a few years ago and, while he is still able to work, he is beginning to need more care at home. In addition, Lucia's father and mother had moved in with her to help with her husband's care, but over the past few years, they have become increasingly frail and now need care themselves. With a houseful of people needing care, Lucia is nearly ready to quit. And you would feel lost without her.

Case D: Monica's 80-year-old mother lives with her. In conversations over the past few years, you've learned that her mother has been diagnosed with Alzheimer's disease and lately her wandering and sometimes confrontational behavior disrupts the household day and night. Six months ago, you offered Monica the chance to take a special extended class in another city to learn some new computer skills. She turned down the opportunity. You are now considering her for a job in another distant branch that would lead to a substantial promotion. When you bring up the subject, Monica merely shrugs and says she can't leave her mother nor take her along. Moreover, Monica says that she will be unable to work extended hours in the future as she has in the past because she is afraid to leave her mother at home any longer than necessary.

IV. WHAT RESOURCES ARE THERE IN THE COMMUNITY? (15 minutes)

A representative of the Area Agency on Aging or Alzheimer's Association can discuss resources that are available in the community for both family caregivers and the older person.

Resources Primarily for Caregivers

- Caregiver support groups
- Caregiver fairs, where social service and health organizations provide resource information
- Case management, where a social worker or nurse manages and monitors services for the relative
- Respite care, which is temporary or periodic care provided in a home, nursing home, assisted living residence, or other type of long term care program so that the usual caregiver can rest or take some time off.

Supervisory Sensitivity Training: a 60-minute program...continued

Examples of the Many Community Resources for Older People

- Adult day care
- Transportation to doctor appointments and shopping
- Meals-on-Wheels
- In-home personal care to help with bathing, dressing, meal preparation
- Chore services for housekeeping and yard work
- In-home assessment of needs
- Home modifications for safety

V. QUESTIONS AND ANSWERS (10 minutes)

The primary focus should be on practical ways to help the supervisor implement what has been learned, specifically, what are the best ways within the corporate culture to accommodate both the needs of the caregiver and the company's needs to get work done in a timely fashion?

A final word about eldercare and business

As this workbook shows, there is much that businesses can do to help employees deal with eldercare issues. From simple distribution of printed materials to training programs for line supervisors, your company's eldercare policies and procedures can be as basic, or as comprehensive, as you want them to be.

With a mature workforce having to provide care for their aging relatives, it is obvious that the organizations that will thrive in the first half of the 21st century will be those whose policies recognize eldercare concerns and work with employees to manage them. That's just how American business met the challenge of working parents in recent decades. And with your company's commitment, American business can successfully meet the challenge of eldercare in the decades to come.

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